Ethics and opportunity costs: have NICE grasped the ethics of priority setting?

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The *Social Value Judgments* consultation document reveals NICE's failure to understand its role in healthcare prioritisation

The National Institute for Health and Clinical Excellence (NICE) has published a draft guideline, *Social Value Judgments: Guidelines for the Institute and its Advisory Bodies (Social Value Judgments)*, which outlines the ethical framework that will guide its decision making in the future.¹ NICE guidance has a profound effect upon the delivery of health care within the National Health Service (NHS) so it is crucial that an overarching guideline such as this is suited to the task that it needs to perform. In this paper we argue that NICE has misunderstood the way in which its advice fits into prioritisation decisions. This misunderstanding is amplified by its views about the ethical principles that should apply to prioritisation and, in particular, its failure to appreciate the role of fair processes in prioritisation.

The national and international standing of NICE means that the definitive version of *Social Value Judgments: Guidelines for the Institute and its Advisory Bodies* is likely to have influence beyond the institute itself. There is much to welcome about the document, not least the acknowledgement that there are important ethical dimensions to NICE's decision making. Indeed, the significance of the document lies in the fact that NICE is attempting to create an explicit ethical framework for funding decisions.

There is, however, much that is of concern. Although John Harris has made some important points about the NICE position on age and sex,² there are other important problems that need to be discussed. First, there appears to be confusion over the nature of the funding decisions taken by NICE and, as a result, the role of its guideline. It is of vital importance that professionals and public alike understand the precise nature of the decisions being taken by NICE and the context in which these decisions function. Second, the document is naive in its use of the ethical principles that are applied to prioritisation and does not seem to grasp why a clear and appropriate procedure is

important for priority setting. These two problems are closely related. If the nature of NICE's decisions within the NHS is unclear or unworkable, its ethical guidance document will lead to confusion and misunderstanding.

WHERE DO NICE DECISIONS FIT?

One of the most worrying aspects of *Social Value Judgments* arises from what appears to be a confusion concerning the nature of the decision making undertaken by NICE and its role in priority setting.

The document states that it is primarily concerned with the ethics of "priority setting". Priority setting by definition is a task that aims to determine which treatments and services are to be given priority vis a vis other treatments and services. Crucially, those tasked with planning and resource allocation in the NHS also have ultimately to ensure that:

- there is a reasonable balance in provision, including services aimed at disease prevention;
- decisions are taken with full awareness of the negative consequences—in other words, opportunity costs are at the heart of priority setting, and
- the decision making processes give all services and patients' groups a fair chance of being prioritised.

It is not possible to achieve the above without *consciously* making choices *between* competing demands. The task of priority setting demands decision makers choose between "A" and "B".

NICE does not, however, make "A" or "B" decisions so priority setting is not a task it carries out. Unlike, say, primary care trusts, NICE is not a budget holder and it does not have to work within the same kind of financial restrictions, so in this sense it does not allocate resources. In its health technology assessment (HTA) programme NICE takes each treatment in turn, making its decision in isolation. The institute does not have to make choices between competing

demands and therefore does not need to concern itself with opportunity cost.

Of course, NICE cannot be criticised for this, nor does it reduce the need for ethical decision making; but the task it undertakes differs profoundly from that of budget holders. The two should not be confused and the final document should clearly reflect this. If the confusion remains there is a danger that the ethical framework will be inappropriate and decision making on such a basis could have serious consequences.

NICE therefore not only needs to get this document right for its own work but also needs to ensure that it does not undermine the work of those actually having to determine priorities in health care. Part of getting it right involves being clear about the nature of the decision making process and having an appropriate ethical framework for that process.

INAPPROPRIATE ETHICAL PRINCIPLES

The institute endorses the four principles approach to biomedical ethics and says its guidance is primarily concerned with the tensions implicit in the principles (NICE,¹ 2.1:10). This, however, demonstrates a degree of naivety about the four principles.

Of the four, the overriding moral principle for setting healthcare priorities is the principle of justice.³ This is because the other three principles, beneficence, non-maleficence, and autonomy, primarily apply to microlevel situations such as the physician/patient relationship.⁴ In a priority setting context where opportunity costs become critical, placing emphasis upon a principle such as autonomy does not capture the morally salient features. Indeed, the very mention of the principle of autonomy and patient choice in a document such as this can give a very misleading impression.

While justice is the appropriate ethical principle, what constitutes the most just or fair outcome is often highly contentious. This is one of the reasons why primary care trusts have established priorities forums.⁵ One of the functions that these forums perform is to bring more general considerations of justice to bear on actual priority setting decisions. The central issue is how services should be weighed against each other under conditions of scarcity: this is clearly a justice consideration.

The institute is clearly aware of these difficulties in stating the importance of using an accountable procedure for arriving at prioritisation decisions. However, there are major problems with the decision making process that they use.

PROCEDURES AND ACCOUNTABILITY FOR REASONABLENESS

NICE follows the influential work of Daniels and Sabin on the importance of "accountability for reasonableness".^{6,7} These authors recognise that while justice is the overriding ethical consideration for priority setting, it is not possible to describe a set of principles that will guarantee a just outcome. They think this is because we live in a pluralist country and cannot expect there to be a consensus about the principles that are relevant for prioritisation. Given this problem, the best solution is to establish a decision making process that legitimises the prioritisation recommended. "Accountability for reasonableness" implies that the decision making process is transparent and that there is the possibility of an appeal. Furthermore, as Daniels and Sabin claim, tough prioritisation decisions should be made by a decision making body that acts on the basis of relevant considerations—this is what makes their recommendations "reasonable".

The institute attempted to respect "accountability for reasonableness" through the establishment of a "Citizen's Council". The council delivered opinions on age, sex, socioeconomic status, and race/ethnicity: opinions that NICE has adopted. There are a number of problems with what has happened. One is that NICE appears to have simply accepted the council's verdicts without considering whether they were based on adequate reasons. "Accountability for reasonableness" requires that decisions are taken on the basis of relevant and publicly accessible considerations.

A second major problem with NICE's use of Daniels and Sabin's work involves the reason for needing "accountability for reasonableness". It is required because we cannot come up with a list of general rules or principles for allocating resources that will produce a just outcome. However, NICE has used the citizen's council to produce rules for priority setting. In other words, NICE has used the citizen's council to do precisely what Daniels and Sabin think we cannot do—generate unproblematic principles that will automatically produce a just prioritisation. This is very worrying when the motivation for emphasising a procedural account is the impossibility of producing rules of this kind.

CONSISTENCY

Most of the responses to *Social Value Judgments* raised issues of ageism and sexism.² Following directly from the

views of the citizen's council, recommendations six and seven in the document allowed considerations of age and sex to influence allocation decisions when these were indicators of benefit or risk. Much of this attention to the issues of ageism and sexism was warranted, not least because the document provided no reasoned account of the how the final position was reached. In this respect, and as an example of the problematic use of the citizen's council, the recommendation on age illustrates the misapplication of the Daniels and Sabin approach.

A second problem is the consistency between the recommendations on age and sex and the other recommendations dealing with specific "controversial" characteristics. Given what has been said about age, it is very hard to see why the same is not said for gender, sexual orientation, socioeconomic status, race, ethnicity, and self infliction. These are all qualities about which it would be inappropriate to have a general policy of discrimination. However, they are also all qualities that arguably can and should sometimes make a difference in resource allocation decisions.

So, while there certainly should be no general policy that privileges one race or ethnicity over another, it may be that race does matter in certain contexts. It may be that part of the argument for prioritising a particular treatment ought to rely heavily on the fact that it affects one particular racial group and that this is of particular concern to that group.

What is important about the problems to do with NICE's use of the citizen's council is that they highlight the connection between the two main concerns we mentioned at the outset: that a lack of clarity about where and how NICE's decisions fit within the decision making processes of NHS priority setting has led to a misuse and apparent misunderstanding of Daniels and Sabin's ethical framework. Being clearer about the role of such an ethical framework will assist in making the decision making process more transparent.

CONCLUDING REMARKS

We enthusiastically welcome NICE's first attempt to explore the ethical issues involved in priority setting and resource allocation. Being clear about the value judgments involved in these decisions will be of great benefit to professionals and the public alike.

However, of overwhelming concern in the *Social Value Judgments* consultation document is NICE's apparent failure to

understand the nature of its role. As a result the role and status of both the document and its ethical content is far from clear.

Perhaps the most important way in which this lack of direction is illustrated is through the inappropriate use of ethical principles and failures of theoretical understanding. Being accountable for the reasonableness of decisions (as a part of procedural justice) brings with it certain requirements. These are not satisfied by a simple appeal to the citizen's council.

There is a role for a document such as this. Part of this role is to be clear about the processes in place and the structure of decision making. Importantly, such a document should also be clear about the role of health technology assessments and other technical or clinical detail concerning particular funding options. Finally, a properly thought out version of this document would provide helpful, well informed discussion of the ethical issues and general social priorities that can assist those who must make actual funding decisions.

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REFERENCES

- 1 **National Institute for Health and Clinical Excellence**. *Social Value Judgments: Guidelines for the Institute and its Advisory Bodies* [draft for consultation]. London: NICE, April, 2005.
- 2 **Harris J**. It's not NICE to discriminate. *J Med Ethics* 2005;**31**:373–5.
- 3 **Beauchamp T**, Childress J. *Principles of biomedical ethics*. Oxford: Oxford University Press, 1994:6.
- 4 **Daniels N**. *Just health care*. Cambridge: Cambridge University Press, 1985:1.
- 5 **Hope T**, Hicks N, Reynolds D, et al. Rationing and the health authority. *BMJ* 1998;**317**:1067–9.
- 6 **Daniels N**, Sabin J. *Setting limits fairly: can we learn to share medical resources?* Oxford: Oxford University Press, 2002.
- 7 **Daniels N**, Sabin J. Limits to health care: fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philos Public Aff* 1997;**26**:303–50.